



IF YOU DONATE BONE MARROW – YOU DONATE LIFE

This is an information in English based on the recruitment and consent brochure published in Norwegian by The Norwegian Bone Marrow Donor Registry, Institute of Immunology, Oslo University Hospital – Rikshospitalet.

ARE YOU WILLING TO DONATE BONE MARROW / STEM CELLS?

- Imagine yourself or one of your loved ones is struck by leukaemia or another serious blood disease. The chance to survive more than a few years is small. Transplantation with stem cells collected from bone marrow or blood may save lives.
- Imagine being able to donate healthy stem cells to a patient and thus save the patient's life.
- If more people are willing to donate stem cells, more patients can find a suitable donor and get a transplant.
- As a volunteer in The Bone Marrow Donor Registry, you may be asked to donate stem cells to a patient.

ARE YOU WILLING TO JOIN THE NORWEGIAN BONE MARROW DONOR REGISTRY?

Only blood donors can join the registry. Please contact your own blood bank. As a volunteer donor you will first be tissue typed. This takes place by a regular blood test. After you have been tissue typed, your data will be entered into the data base of The Bone Marrow Donor Registry.

When there is a patient in need of a transplant, we will search for a donor with the same tissue types as the patient.

Stem cells are collected from the donor at the time of the transplant.

WHO MAY DONATE STEM CELLS?

If a sister or a brother has the same tissue types as the patient, she or he will be the best donor. If the patient does not have a sibling or other close relatives with the same tissue type, one would need to search for an unrelated donor with the same tissue types as the patient.

WHAT IS BONE MARROW AND WHAT ARE STEM CELLS?

Bone marrow occupies the interior of bones. The marrow contains numerous bone marrow cells including the immature stem cells. Stem cells are normal constituents of the bone marrow. Stem cells are progenitors for red and white blood cells and blood platelets. They are therefore referred to as blood-forming stem cells. When stem cells divide, they mature, and the mature blood cells are found in the blood circulation.

WHAT IS BONE MARROW TRANSPLANTATION?

Bone marrow transplantation means that a patient receives blood-forming stem cells from a suitable healthy donor. Bone marrow transplantation is also referred to as stem cells transplantation.

About a week prior to a transplant, the patient receives a treatment aiming at destroying the patient's own bone marrow cells. Strong chemotherapeutics or irradiation is used for this purpose. Afterwards, the patient receives healthy stem cells from the donor through an intravenous infusion, just like a regular blood transfusion. Previously, the donor's stem cells have been collected in a transfusion bag after the collecting from the bone marrow or the blood. The transfused stem cells find their way to the patient's bone marrow and "settle down" there. The purpose of the transplant is that the new stem cells should establish a new production of blood cells and blood platelets in the patient.

WHAT KIND OF PATIENTS IS STEM CELL TRANSPLANTED?

Most of the patients suffer from leukaemia (blood cancer) or other serious blood diseases, but patients with certain forms of rare inborn metabolic disorders, inborn immunodeficiency, or extensive irradiation exposure may also be treated. Stem cell transplantation may be a life saving treatment in these instances.

CAN I WITHDRAW AT ANY TIME?

You may withdraw at any time before the transplant, and you do not need to give a reason.

HOW DO I DONATE STEM CELLS FROM THE BONE MARROW?

How is bone marrow harvested?

Bone marrow harvests take place in a hospital with good experience in bone marrow harvesting. First, the bone marrow donor receives a full anaesthesia. A needle is punctuated into the dorsal part of the pelvic bone on both sides. The bone marrow, which looks like blood, is aspirated through the needle to be collected in a transfusion bag. Only a small fraction of the donor's bone marrow is aspirated, and this fraction is renewed within a few weeks. The harvesting takes about one hour to complete. The donor can go home the next day.

Is there a pre-treatment of a bone marrow donor?

No, there is no special pre-treatment. The donor cannot eat after midnight the night before the harvesting.

Does it hurt to donate bone marrow?

Everyone will experience pain and tenderness in the upper dorsal part of the hip region some days after the harvesting. The donor should for about a week be careful when lifting heavy items or exercising. There will be no or only small scars after the procedure.

Is it dangerous to donate bone marrow?

If you are healthy, there are only minor risks related to the bone marrow harvesting, and complications are rare. The donor will always go through a health examination prior to the harvesting, and he/she will have an extensive information session where all aspects of marrow donation are discussed.

HOW DO I DONATE STEM CELLS FROM THE BLOOD?

How can stem cells be in the blood circulation?

Normally, stem cells are found in the bone marrow, but stem cells can under certain conditions be found in the blood circulation after a special treatment. The donor is given injections of a so-called stem cell growth factor every morning in 5 days, and this causes some of the stem cells to enter the blood circulation. Currently, a stem cell growth factor called G-CSF is used. G-CSF is a component which normally can be found in the body and which stimulates stem cells. When an adequate number of stem cells are detected in the blood circulation after treatment with G-CSF, stem cells can be collected. Stem cells circulation in the blood return to the bone marrow shortly after termination of G-CSF treatment.

How are stem cells collected from the blood?

Stem cells from the blood circulation are collected by means of an apheresis machine. The procedure takes place in a hospital with good experience in the usage of this machine. Blood is collected in a way similar to blood collection. The externally circulated blood is centrifuged in the apheresis machine, a process which allows the stem cells to be collected. The rest of the blood is given back to the donor. The process lasts a few

hours, and it might need to be repeated the next day to collect enough stem cells. Only a small fraction of the stem cells is collected, and stem cells renew within a short time.

Is it painful or dangerous to donate stem cells?

There is not particularly more discomfort than donating blood, and the risk is very small. Since the procedure lasts a few hours, you might get tired. Blood circulation and blood values are followed carefully, and the apheresis will be terminated if the donor is not feeling well.

Is there any discomfort or danger related to G-CSF treatment?

Daily injections of G-CSF is a low risk procedure. Almost all donors experience side effects in the form of pain in the bones. Many experience fatigue, and some might have a slight fever and/or headache. The discomfort can be treated with paracetamol or stronger painkillers. The majority can attend work during G-CSF treatment, but some are away from work a few days. Everyone goes through an extensive health examination and information session prior to the treatment.

HOW DO I BECOME A STEM CELL DONOR?

If you are between 18 and 40 years of age, you can contact your local blood bank and ask to become a volunteer in The Bone Marrow Donor Registry. You may then be a volunteer donor in The Bone Marrow Donor Registry until the age of 55 years. To be able to tissue type you, we need a blood sample, for instance drawn in relation to a regular blood donation.

WHAT IS A TISSUE TYPE?

A tissue type is determined by molecules on the surface of the body's cells. These molecules play a central role in the immune defence. It is generally known that there has to be blood group compatibility when a blood transfusion is conducted. When performing stem cell transplantation, identical tissue types are required.

WHY DO WE NEED MANY STEM CELL DONORS?

There are many million different tissue types. It is therefore difficult to find a donor with the same tissue types as a patient. More volunteer stem cells donors make it possible to find a donor to more patients. The likelihood that you will be selected to donate stem cells is approximately 1-2 in 1,000 per year.

HOW AM I INFORMED THAT I MAY DONATE STEM CELLS?

If your tissue type seems identical to a patient, will we ask for a new blood sample for a more detailed tissue typing. If your tissue type turns out to be sufficiently similar to the patient's tissue type that you can be selected for donation, you will be asked to attend a donor information session and go through a health examination. At this stage we will, among other issues, discuss whether you may donate stem cells from the bone marrow or from the blood.

As a donor in The Bone Marrow Donor Registry, you may also be asked to donate blood, white blood cells, or blood platelets to patients with special requirements, most often in relation to stem cell transplantation. This will be addressed individually in each single case.

HEALTH INFORMATION

Information about your name, social security number (unique person number), gender, blood bank, blood group, some of the blood banks' standard virus and bacteriology tests, and your tissue types will be filed in the electronic data base of The Bone Marrow Donor Registry at The Institute of Immunology, Rikshospitalet. The Norwegian Bone Marrow Registry has concession from The Data Inspectorate. Your rights are outlined and protected by the Personal Health Data Filing System Act (*Helseregisterloven*) and the Personal Data Act (*Personopplysningsloven*). Medical and practical information with relevance for a possible donation, and which is recovered during work up of you as a potential donor, may also be filed. The information is treated

confidentially by personnel with professional secrecy. A unique identification number, assigned to you by The Bone Marrow Donor Registry, substitutes your name and social security number in all our correspondence with other registries and transplantation hospitals. After you have left The Bone Marrow Donor Registry, your data will be stored in a historical file for 30 years according to regulation concerning requirements for quality and security standards for human cells and tissue for usage in humans.

To allow as many patients as possible to be stem cell transplanted, we need many thousand donors in Norway. We have an extensive collaboration with bone marrow donor registries all over the world, and we have therefore access to millions of donors. We are at the same time providing donors for patients in other countries.



The Bone Marrow Donor Registry was established in 1990. Bone marrow donation was the only alternative at that time – therefore the name. Later, the possibility to donate stem cells collected from the blood has become an alternative for bone marrow donation.



The Bone Marrow Donor Registry is a result of collaboration between all blood banks in our country, Institute of Immunology, and The Medical Department at Rikshospitalet.



The Bone Marrow Donor Registry is financed by The Cancer Society.



Thank you for taking your time to read this brochure. We hope that you will ask your blood bank to become a donor.